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Testing a Model Predicting Depression, Anxiety and Stress in Parents of Children with
Down Syndrome

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Statement of Sources

I declare that this report is my own original work and that contributions of others have been
duly acknowledged.

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Abstract

Down syndrome is a disorder characterised by mild to moderate intellectual impairment, short stature and certain facial characteristics (Gokhale, Solanki & Agarwal, 2014). Caring for a child with Down syndrome can be challenging, placing immense strain on parents and negatively impacting their mental health. Falk, Norris and Quinn (2014) created a model (Model A) predicting distress in parents of children with Autism Spectrum Disorder (ASD), suggesting that parental cognitions, social support and economic support play a mediating role between parental distress and their child's ASD severity and externalising behaviours. Further validation of Model A suggested that it might have universal applicability (Bones, 2017). In order to test this, 211 parents of children aged between 4 and 17 with Down syndrome, ADHD or no disorder were recruited for the current study. Model A predictors were found to hold in the whole sample when regression analysis was performed, however low correlations were found between socioeconomic factors and distress in the parents of Down syndrome children sample, indicating that an alternative model may better predict distress in this population. The results of the study support the efficacy of parent-focused interventions and the use of CBT in providing beneficial outcomes for both Down syndrome parents and their children.

Down syndrome is the most common genetic cause of intellectual disability and is characterized by mild to moderate intellectual impairment, short stature and certain facial characteristics, including a flattened facial profile (Gokhale, Solanki & Agarwal, 2014). One in every 691 babies is born with Down syndrome worldwide, with a prevalence of 8.3% per 10,000 births (Onyedibe, Ugwu, Mefoh & Onuiri, 2018). In Australia around 270 babies are born with the disorder every year, with the overall Down syndrome population being over 13,000 individuals (Down Syndrome Australia, 2013).

Down syndrome results from the presence of an extra copy of chromosome 21 (O'Toole et al., 2016). There is no known cause for this abnormality, and it appears to occur by chance. There is no cure for Down syndrome, however child-specific interventions can improve functioning and increase later quality of life. Communication interventions are commonly used to assist Down syndrome children, with language acquisition being a critical issue for most children with the disorder (Neil & Jones, 2018). There is often a mismatch between the non-verbal abilities of Down syndrome children and their speech and language abilities, with their cognitive capacity being a great deal higher than what their expressive language would suggest (O'Toole et al., 2016). Early language interventions are critical for the cognitive and social development of these children, helping Down syndrome children reach the potential reflected by their superior non-verbal abilities. These interventions can provide Down syndrome children with the means to communicate with others, increasing their independence and improving all aspects of their life, including increasing their educational and employment opportunities (Neil & Jones, 2018).

Parents of Down syndrome children play an extensive role in ensuring their child gets the treatment they need. Parental involvement in child interventions is considered integral to the effectiveness of programs and the functional outcomes of the child (Patton & Hutton, 2016). Many interventions geared towards Down syndrome children focus on supporting

communication development during parent-child interactions, with parental responsiveness to their child's language attempts being considered integral to their child's language development (Lorang, Sterling & Schroeder, 2018). Parent training interventions such as responsive teaching can provide parents of children with developmental delays with the tools to become more responsive towards their children (Mahoney, Perales, Wiggers & Herman, 2006). Those who utilise this training can greatly enhance their child's cognitive functioning and social-emotional wellbeing. If the time taken undergoing such training is to be effective for the child, however, parents must properly implement the techniques at home (Roz, Hernandez, Graziano & Bagner, 2015). Parents of children with disabilities must work to integrate such programs into their everyday lives; they must find time to continue therapy at home themselves while still meeting other work and family demands (Patton & Hutton, 2016).

Having a child born with a developmental disability, such as Down syndrome, brings with it a number of challenges. Parents need to seek and pay for specialized care, come to terms with their child's diagnosis and limitations, and cope with the added and extended care they will need to provide throughout the child's life (Glidden, Billings & Jobe, 2006). Parents often experience feelings of guilt and loss in the wake of their child's diagnosis, with the disorder signifying that their child will not have the same opportunities as their typically developing peers (Glidden, Billings & Jobe, 2006). Parents of children with developmental disabilities have reported feeling isolated, socially excluded and under increased pressure due to the caregiving they provide (Hamlyn-Wright, Draghi-Lorenz & Ellis, 2007). They face stigmatism from others, whose negative attitudes and behaviours towards their child can lead parents to withdraw from those around them and conceal the difficulties they face (Cantwell, Muldoon & Gallagher, 2015). The strain this places on parents can be immense and can negatively impact their mental health, leading to increases in stress, anxiety and depression.

Depression, Anxiety and Stress

Depression is a mood disorder that affects both the mind and the body, and is characterized by low mood, loss of interest in activities and lack of energy (Beck & Alford, 2009). Anxiety refers to an emotional state where one experiences ongoing feelings of panic, worry and fear, accompanied by physiological arousal (Kovacs & Borcsa, 2017). Stress refers to feelings of emotional, physical or mental tension resulting from demands that exceed what an individual feels they can cope with (Hayes & Watson, 2012). These factors are collectively termed distress in this study. They are reportedly more prevalent for parents of children with developmental disorders, compared to those with typically developing offspring. Feldman et al. (2010), for example, found that parents of children with developmental delays, such as Down syndrome, had higher rates of depression than those with typically developing children. Gupta (2007) found higher levels of stress amongst parents of children with developmental disorders or ADHD in comparison with parents of typically developing children. In a study conducted by Gallagher, Philips, Oliver and Carroll (2008) 63% of the parents of children with intellectual disorders met the criteria for a possible depression diagnosis, and 75% met the criteria for a possible anxiety diagnosis. Amongst their sample of parents with typically developing children, only 7% met the criteria for depression, and 10% for anxiety.

Down syndrome is often considered to be an “easier” disorder for parents to cope with, as children with Down syndrome tend to be easy going, compliant and display fewer behavioural problems than children with other disorders such as Autism or ADHD (Mitchell, Hauser-Cram & Crossman, 2015). However once controlling for demographic factors, including parental age, maternal education and social support, parental stress levels have been found to be similar to those experienced by parents of children with other intellectual disorders (Mitchell et al., 2015). Roach, Orsmond and Barrett (1999) found that despite the

fact that Down syndrome children are considered to be on-par with typically developing children when it comes to positive mood and adaptability, parents were still significantly more likely to perceive their Down syndrome child as being demanding, distractible and unable to meet expectations. While the diagnosis of Down syndrome was not found to contribute to parental stress in this study, the caregiving demands of raising a child with the disorder were linked to depression and difficulties in parenting competency. Griffith, Hastings, Nash and Hill (2009) conducted a study where mothers of children with Down syndrome and Autism were matched based on age, gender and communication skill level of their child. No significant difference was found in depression and anxiety levels between mothers in the two groups, indicating that it is not the disorder itself that contributes to different levels of psychological distress in parents, but how impacted their child is by the disorder, and how well the parents are able to manage this.

The higher rates of depression, anxiety and stress found in parents of children with developmental disorders such as Down syndrome, can negatively impact their health and capacity to function. High levels of stress and anxiety can compromise the immune system, making individuals more susceptible to infection and disease, while depression has been linked to heart problems and an increased risk of type 2 diabetes (Maes et al., 1998; Morgan et al., 2013). Along with these physical effects, parental depression, anxiety and stress has been found to lead to inconsistent and ineffective child management techniques, increases in negative appraisals of child behaviours, an increased risk of family discord, and less positive interactions between parent and child (Burke, 2003; Hastings, 2009; Ramchandani et al., 2011; Moore, Whaley & Sigman, 2004).

In this way, the distress experienced by these parents impacts not only the parent's ability to function, but also the functional abilities of the children in their care (Margalit & Kleitman, 2007). Esbensen, Mailick and Silverman (2013) found that improvements in

maternal mental health positively impacted Down syndrome children, increasing their ability to function, reducing behavioural problems and improving health outcomes. They proposed that this might be due to better maternal psychological functioning enabling mothers to provide more support for their child; with better mental health mothers are able to attend to behavioural and functional problems when they occur, ensuring their child gets the assistance they need. In a study conducted by Neece, Green and Baker (2012) involving parents of children with and without developmental delays, support for a bidirectional relationship between parental stress and child behaviour problems was found. Not only do child behaviour problems appear to contribute to parental stress, parental stress appears to cause an increase in child behaviour problems. This is concerning considering the fact that early behavioural problems have been found to be a risk factor for later psychopathology (Neece, Green & Baker, 2012). Children with intellectual disabilities have an increased risk of developing psychiatric disorders, with research suggesting that the prevalence of psychopathology for these individuals is 3-4 times higher than that for the general population (Tonge & Einfeld, 2000). With parental distress contributing to these negative outcomes, interventions focused on parental mental health have the potential to not only help the parents of children with Down syndrome, but to also improve functional and emotional outcomes for their child.

Very little research has gone into parent-focused interventions for parents of children with Down syndrome, as most interventions focus on improving the communication capacities of the child. Family-focused interventions have been found to benefit parents of children with disorders more broadly. When the therapist works in collaboration with the parents to fit therapy programs into family routines and facilitates ongoing social support parents feel better able to persist with therapy goals and more competent in managing their child's developmental difficulties (Patton & Hutton, 2016). Interventions focusing on family

adaption and empowerment have also been found to be beneficial. Parents of Down syndrome children involved in such interventions develop more positive perceptions of their child, feel more confident about their parenting abilities and display lower levels of distress (Pelchat, Bisson, Ricard, Perreault & Bouchard, 1999). Such interventions are not, however, parent centric, nor do they provide specific parent-focused targets.

Predicting Parental Distress

In order to provide effective interventions for parents of children with Down syndrome, we need to know what factors predict mental health outcomes in this population. Child behaviour and functional capacity have been the focus of most research looking at parental distress in parents of children with Down syndrome and other disorders. Children with developmental disorders such as Down syndrome tend to display more behavioural problems and functional difficulties than their typically developing counterparts, which has been found to lead to higher levels of parental stress (Mitchell, Hauser-Cram & Crossman, 2015). A number of additional factors have been identified as contributing to distress in studies involving parents of Down syndrome children. Demographic factors appear to play a significant role, with socioeconomic factors such as low income being found to lead to higher levels of stress (Mitchel et al., 2015). Social support has been found to mediate the relationship between child behaviour problems and parental distress, increasing the parent's ability to cope with their child's disorder (Feldman et al., 2010). Additionally, parental locus of control has been found to be predictive of depression, anxiety and stress in parents of children with intellectual disorders including Down syndrome (Lloyd & Hastings, 2009).

While a number of factors have been examined in regards to distress in parents of children with Down syndrome, most studies focus on only one or two factors. This makes it difficult to determine whether these factors would still be significant predictors of distress once more variables were used. It is possible that factors such as perceived lack of control

only adds predictive value when variables such as social and demographic factors are not considered. To fully understand what factors contribute to distress in parents of children with Down syndrome, simultaneously examining multiple factors would be beneficial. This would allow us to determine which factors remain significant predictors in the presence of others, and whether some factors that appear highly predictive on their own, actually play a lesser or different role once others are considered.

Contributing factors including social support, demographics, perceived locus of control and behavioural problems are not exclusive to parents of Down syndrome children, and have been found to impact parents of children with other chronic disorders, including Autism (Falk, Norris & Quinn, 2014). Bones (2017) conducted a study validating a model created by Falk et al. (2014) that predicted anxiety, depression and stress in parents of children with Autism, incorporating factors found to predict similar outcomes in parents of Down syndrome children. The model (Model A) suggested that parental cognitions, social support and economic support played a mediating role between parental distress and their child's Autism severity and externalising behaviours.

The original study conducted by Falk et al. (2014) used data collected from 250 mothers and 229 fathers to determine which factors best predicted distress in parents of children with Autism Spectrum Disorder (ASD). Hierarchical regression was used to analyse 17 factors, with those found to be the best predictors being externalising behaviours, Autism severity, parental cognitions, social support and economic support. These factors were subsequently used to create Model A, the terminology of which has also been adjusted to ensure the model can be used for populations other than ASD (Bones, 2017). Figure 1 (Appendix A) shows the adapted model.

Structural equation modeling was used to test Model A, with results indicating a good fit for the data (Falk et al., 2014). Bones' (2017) study provides further support for the model,

with the same factors being found to predict parental distress and Model A again being found to be a good fit for the data. The results of Bones' (2017) study also indicated that Model A might be able to predict parental distress more generally, and be applicable to parents of children with other disorders, such as Down syndrome. Further research into this finding would contribute towards determining whether Model A could be applied universally, and used to inform parent-focused interventions that help prevent and treat parental distress in parents of children with Down syndrome and other disorders.

Variables in Model A

Child Externalised Behaviours

Externalised behaviours in children are characterized by poor impulse control, aggression, hostility and defiance (Tully et al., 2017). Children born with intellectual disabilities are more likely than their typically developing peers to exhibit these problematic behaviours and be diagnosed with a psychiatric disorder such as anxiety or obsessive-compulsive disorder (Dyken, Shah, Sagun, Beck & King, 2002). While displaying fewer behavioural problems than children with other intellectual disorders, children with Down syndrome are more likely to exhibit stubbornness, oppositionality and inattention than their typically developing counterparts. In particular, their tendency towards inattention can cause difficulties in administering interventions and ensuring therapy sessions are effective (Dyken et al., 2002). Behavioural problems have been found to increase stress levels in parents of children with Down syndrome and other intellectual disorders, with higher levels of behavioural issues resulting in higher levels of parental distress (Blancher & McIntyre, 2006). While Falk et al. (2014) and Bones (2017) found externalising behaviours to be a significant predictor of parental distress, parental cognitions and socio-economic support were found to be better predictors in this regard.

Socio-economic Factors

Social Support

Social support refers to both verbal and non-verbal communication that reduces feelings of uncertainty in the receiver. Uncertainty can relate to the person's situation, self, the other or the relationship, with social support enhancing a person's sense of control in these areas (Ko, Wang & Xu, 2013). This support can come from friends, family, the ability to dedicate time to leisure activities, community programs and professional assistance and advice (Siklos & Kerns, 2006).

Social support is more readily available to parents of children with Down syndrome compared to parents of children with other disorders (Mitchell, Hauser-Cram & Crossman, 2015). There is more information available about Down syndrome than other developmental disorders, both from professionals and online, and parents have better access to early interventions (Mitchell, Hauser-Cram & Crossman, 2015). This is a factor that contributes to the "Down syndrome advantage" found in a number of studies, indicating that distress levels may be a lot higher in those parents not utilising the social support available to them, or not having access in this regard.

Economic Support

Economic support appears to play a major role in distress levels amongst parents of children with Down syndrome. As found by Mitchell, Hauser-Cram and Crossman (2015), once demographic factors are taken into account, parents of children with Down syndrome tend to have similar levels of stress to parents of children with other disorders. Economic support is one such demographic factor; financial security appears to reduce the distress that accompanies having a child with Down syndrome to the point where parental stress levels are similar to those experienced by parents of children without a disorder. This is thought to be due to the fact that mothers of Down syndrome children tend to be older, thus are more likely

to be highly educated, more likely to have higher paid jobs and ultimately more likely to be financially secure (Mitchell et al., 2015). In turn, they are more likely to have the means to pay for specialized treatments, out of home care and the medical expenses required for their Down syndrome child.

Maladaptive Parental Cognitions

As indicated by the results of Bones' (2017) and Falk et al.'s (2014) research, maladaptive parental cognitions may be better predictors of parental distress than child specific factors, such as functional capacity and behavioural problems. In a study conducted by Hill and Rose (2009) parental cognitions were found to explain 61% of the variability in stress amongst parents of children with intellectual disabilities.

Two parental conditions found to have predictive value for distress in parents of children with Autism are parental locus of control and perceived limit setting ability (Falk et al., 2014). These same cognitions could help explain distress differences in parents of children with Down syndrome. Our cognitions impact how we handle situations; we respond differently depending on how we perceive what occurs around us (Hassall, Rose & McDonald, 2005). Thus, differences in how parents process situations involving their Down syndrome child may lead to different levels of distress.

Parental Locus of Control

Parental locus of control refers to how parents perceive control in regards to their children, whether they believe in their own capacity to control their child's behaviour, or whether it is perceived as beyond their control (Lloyd & Hastings, 2009). Parents with a more internal locus of control tend to display less distress than those with an external locus of control. This is due to the fact that as long as a child's behaviour is perceived as controllable, parents feel capable of implementing strategies that may reduce behavioural problems. As

soon as control is perceived as external, parents can become overwhelmed by their child's behaviour and feel unable to cope (Lloyd & Hastings, 2009).

Parental locus of control has been found to play a role in distress outcomes in parents of children with developmental disorders (Lloyd & Hastings, 2009). External parental locus of control has been shown to predict issues in adapting to having a special needs child, as well as being associated with higher levels of parental stress. The studies conducted by Falk et al. (2014) and Bones (2017) both found evidence of parental locus of control acting as a mediator between externalized behaviours and parental distress in parents of children with ASD, which is consistent with results reported for parents of children with Down syndrome.

Perceived Limit Setting Ability

In the context of parenting, perceived limit setting ability refers to a parent's beliefs concerning establishing and maintaining parameters of acceptable behaviour for their children (Reed, Howse, Ho & Osborne, 2017). Parents who feel competent in their parenting role have been found to experience less distress, due to the fact that they feel better able to succeed in managing their child's behaviour (Kuhn & Carter, 2006). The research conducted by Falk et al. (2014) and Bones (2017) indicated that perceived limit setting ability plays a mediating role between externalising behaviours and parental distress in parents of children with ASD, with lower perceived ability leading to higher levels of distress. While previous research into distress in parents of children with Down syndrome has not addressed perceived limit setting ability as a possible contributing factor, Bones' (2017) findings regarding its role in not only distress in parents of children with ASD, but in parents of typically developing children, supports exploring its role in this new sample.

Down syndrome severity

For this study, the variable used to measure Autism severity in Bones (2017) and Falk et al.'s (2014) research – child social and interpersonal deficits – was substituted for a measure of Down syndrome severity.

Down syndrome is a disorder that impacts some individuals more than others (Määttä, Tervo-Määttä, Taanila, Kaski & Iivanainen, 2006). In some cases intellectual impairment can be very mild, however the majority of Down syndrome individuals will need lifelong assistance. Functional and communicational deficits are common, with more severe issues in these areas being related to more severe behavioural problems (Määttä et al., 2006). Lower functional capacity in children with Down syndrome has been associated with higher levels of parental stress, anxiety and depression. Therefore, a measure of functional capacity appeared to be the most accurate way of determining disorder severity for this sample.

Aims and Hypotheses

The current study aimed to extend on the findings of Bones (2017) in a number of ways. Firstly, the current study examined whether the previously mentioned model validated by Bones (2017) could predict the mental health outcomes of parents of children with Down syndrome. It was hypothesized that the model would account for a significant proportion of the variance in predicting the mental health outcomes of parents with Down syndrome children. Secondly, the current study recruited both parents of children with Down syndrome and parents of children without Down syndrome in order to determine whether the model could be applied universally. While previous research has found that parents of Down syndrome children have higher levels of depression, stress and anxiety than parents of children without a disorder (Mitchell, Hauser-Cram & Crossman, 2015; Griffiths et al. 2009), Bones' (2017) results regarding Model A indicated that the same factors predictive of distress in parents of children with Autism were predictive of distress in parents of children without a

disorder. Based on this finding it was suggested that these predictors may be universal, with different scores on each of these variables predicting different levels of parental distress, and not that different parent groups were impacted by different factors. It was therefore hypothesised in the current study that Model A would demonstrate invariance between parents of children with Down syndrome and parents of developmentally normal children. The study also aimed to investigate the Down syndrome advantage in regards to the factors included in Model A. Based on Mitchell, Hauser-Cram and Crossman's (2015) findings regarding socioeconomic factors contributing to this advantage, it was hypothesised that parents of children with Down syndrome would experience higher levels of social and economic support than parents of children with other disorders such as Attention Deficit Hyperactivity Disorder (ADHD).

Method

Design

The study used a cross-sectional, correlational design. The independent variables were social support, economic support, Down syndrome severity, child behaviour (conduct problems, hyperactivity and aggression), parental cognitions (perceived limit setting ability and parental locus of control), and demographic information (parental age, marital status, parental education level, parental income, number of children, sex of the child and age of the child). The dependent variables were depression, anxiety and stress. Independent samples *t*-tests were used to compare parents of children with Down syndrome and parents of children with ADHD on the socioeconomic, parental cognitions, child behaviour and distress variables.

Ethics

Ethical approval was gained through the Tasmanian Social Sciences Human Research Ethics Committee (H0017272; Appendix B). As participants were asked questions regarding

mental health and experiences of parenting, the study had the potential risk of evoking anxiety or causing discomfort. A number of mechanisms were put in place, however, to ensure the study complied with the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, 2018). Firstly, this risk factor was outlined in the information sheet provided (Appendix C), along with the potential benefits, ensuring informed consent and that participants could choose not to participate. Secondly, participants were able to withdraw from the study at any time prior to the submission of the questionnaire, with no penalty. Thirdly, participants were provided with the contact details of the researchers, as well as contact details for Lifeline and BeyondBlue should they have any questions or experience any discomfort.

Participants

The study included parents of children with Down syndrome, ADHD or no disorder aged between 4 years 0 months and 17 years 11 month. The parent confirmed Down syndrome or ADHD diagnosis. Parents of children without Down syndrome were included in order to determine whether Model A can differentiate between parents of children with Down syndrome and parents of children without Down syndrome. Parents of children with ADHD were included in order to evaluate the Down syndrome advantage by comparing to a parent group typically found to experience elevated levels of distress.

The study aimed to recruit at least 230 participants in order to reach a power level of .95 and detect a moderate effect at .3. 211 participants responded to the survey, 45 had children with Down syndrome, 44 had typically developing children, and 135 had children with ADHD. 13 of these parents had children with both Down syndrome and ADHD. All participants were retained for analysis. Categorical demographic factors for parents and children can be found in Tables 1 and 2 (Appendix D). Continuous demographic factors can be found in Table 3 (Appendix D).

Participants were recruited via a number of Down syndrome support groups on Facebook and websites, via University of Tasmania noticeboards, in some University of Tasmania Division of Psychology lectures, the Australian Psychological Society, medical practitioners, and through the Department of Education. A copy of the advertisement used can be found in Appendix E.

Materials

The materials used in the study were the same as those used by Bones (2017), with the only exception being the substitution of the Autism measure with a Down syndrome severity scale.

The short version of the Depression, Anxiety and Stress Scale (DASS-21: Lovibond and Lovibond, 1995) was used to measure the dependent variables. The DASS-21 contains three 7-item scales measuring depression, stress and anxiety, with each question being presented as a statement. Participants were asked to indicate how well the statements applied to them over the last week, using a 4-point Likert scale. Scores ranged from 0-21, with higher scores indicating higher levels of distress. Cronbach alpha scores for each of the three scales included in the DASS-21 indicate adequate internal consistency; .81 for depression, .73 for anxiety and .81 for stress (Lovibond & Lovibond, 1995).

The Berlin Social Support Scale (BSSS: Schwarzer & Schulz, 2000) was used to measure social support. This measure contained 52 items, each rated using a 4-point Likert scale ranging from 1 “strongly disagree” to 4 “strongly agree.” Each item was presented as a statement, for which participants indicated how much they agreed. The BSSS contains six subscales, one of which, perceived social support, was included in this study (Schwarzer & Schulz, 2000). Scores ranged from 8-32, with higher scores indicating higher levels of social support. Cronbach’s alpha indicated adequate internal consistency for each subscale, with values ranging from .63 to .83 (Schwarzer & Schulz, 2000).

Economic support was measured using a 2-item scale developed by Falk et al. (2014). A copy of the questions can be found in Appendix F. These items were rated using a 5-point Likert scale, ranging from 1 “strongly disagree” to 5 “strongly agree.” Cronbach’s alpha indicated adequate internal consistency, with a value of .84 (Falk et al., 2014).

The Strengths and Difficulties Questionnaire (SDQ: Goodman, 2001) was used to assess child behaviour. The measure contains 25 items using a 3-point Likert scale and has five subscales, each consisting of five questions. The conduct problems and hyperactivity subscales were included in the study, with possible scores for both subscales ranging from 1 to 10. Higher scores indicated a higher degree of perceived behavioural problems. Cronbach alpha scores were .66 for conduct problems and .65 for hyperactivity, indicating adequate internal consistency.

A single item developed by Falk et al. (2014) was used to measure aggressive behaviour. This item was *often aggressive or violent towards adults*. It uses a 3-point Likert scale ranging from 1 “not true” to 3 “certainly true.”

Parental cognitions were measured using the Parent-Child Relationship Inventory (PCRI: Gerard, 1994). The PCRI is a questionnaire containing 78 items measured using a 4-point Likert scale ranging from “strongly agree” to “strongly disagree” (Gerard 1994). The PCRI consists of seven subscales, one of which, perceived limit setting, was included in this study. This subscale consisted of 12 questions, with possible scores ranging from 12-48. Higher scores indicated lower perceived limit setting ability. Cronbach’s alphas for all subscales in this measure have been found to be above .70, indicating good internal consistency.

A shortened form of the Parental Locus of Control Scale (PLOC: Campis, Lyman & Prentice-Dunn, 1986) was used to determine parental locus of control. The shortened version of the PLOC contains 24 items using a 5-point Likert scale ranging from “strongly disagree”

(1) to “strongly agree” (5) and has 4 dimensions: Parental efficacy, Parental Responsibility, Child Control of Parent’s Life and Parental Control of Child’s Behaviour (Campis, Lyman & Prentice-Dunn, 1986). Scores ranged from 25-125, with higher scores indicating a more external locus of control. The measure has good internal consistency, with a Cronbach alpha value of .92.

Down syndrome severity was measured using a scale developed for this study. A copy of this scale can be found in Appendix G. The scale is based on the Functional Independence Measure for Children (WeeFIM: Msall et al., 1994) and the Pediatric Evaluation of Disability Inventory (PEDI: Haley, 1992). While still covering each subscale included in the WeeFIM and the PEDI, this scale includes fewer items, making the measure more manageable for those completing the questionnaire. The scale comprises 22 items rated as either “yes”(1) or “no”(0) and has 3 dimensions: Self-care, mobility and social competence. Possible scores ranged between 0 and 22, with higher scores indicating higher functional capacity of the child.

Demographic information was obtained at the start of the questionnaire. A copy of the demographic questionnaire can be found in Appendix H.

Procedure

Those interested in the study were able to access the questionnaire online via a link provided in the advertisement. Once reaching the website, the participant was provided with details regarding the purpose, method and any possible risks and benefits to completing the study. Participants could begin the questionnaire once they finished reading this information sheet. If parents had more than one child with Down syndrome, they were asked to complete the sections of the questionnaire that are child specific in relation to only one child, using the same child for each section. Parents of typically developing and ADHD children were also asked to complete the survey in regards to only one of their children. Submission of the

questionnaire implied consent. Upon completion of the questionnaire, participants were given the option to enter a draw to win one of four \$50 Coles-Myer vouchers.

Data Analysis

Assumptions of normality, linearity and homoscedasticity were assessed prior to running statistical analysis. Box-plots revealed outliers for the depression, stress, social support and limit setting ability measures. These outliers were not removed, as doing so did not change model outcomes. Additionally, normal distributions were not expected for depression and stress considering the nature of the populations researched. Model A was unable to be tested without these variables, so despite problems with normality they were retained in the analysis. Social support and conduct problems were both positively skewed, while aggression was negatively skewed. Transforming these variables did not improve model output so the original data was retained in analysis.

Due to the small sample size, it was not possible to conduct structural equation modeling. Conducting regression analysis on the Down syndrome parent sample was also constrained by the sample size. Regression analyses using only those factors that were significantly correlated with the outcome variables were also considered, however due to the high number of significant correlations there would still be a power issue.

While regression analyses could not be performed on the Down syndrome parent sample alone, forced entry regressions using the entire sample were performed in order to determine whether the same factors in Model A predicted depression, anxiety and stress in a new sample. If it holds in a heterogeneous sample comprising parents of children with Down syndrome, ADHD and no disorder, then this lends weight to the idea that the model predicts universal parental distress and not just parental distress for those with children with ASD only, as was suggested by Bones et al. (in press).

Results

Table 4 includes the means, standard deviations and internal reliability coefficients for all indicators included in the analyses.

Table 4

Means, Standard deviations and Cronbach's Alphas for Model Indicators in Whole

Sample

<i>Variable</i>	<i>M</i>	<i>SD</i>	<i>α</i>
Depression	10.85	8.75	.76
Anxiety	12.15	10.46	.84
Stress	7.50	7.93	.83
Social Support	20.68	10.56	.92
Economic Support	5.00	3.48	.68
Conduct Problems	8.31	6.08	.82
Aggressive Behaviour	1.2	.99	
Limit Setting Ability	22.22	14.04	.28
Parental Locus of Control	42802	29.87	.73
Down Syndrome Severity	32.48	5.59	.89

Note α = Cronbach's alpha

The Cronbach's alpha value for limit setting ability was .28, indicating an issue with internal reliability. This indicator was retained in the analysis due its role as an indicator in the original model. The limit setting ability measure has previously achieved acceptable levels of internal reliability (Gerard, 1994), however Bones (2017) had a similar issue with the measure, with a Cronbach's alpha value of .3.

For parents of children with Down syndrome and parents of children without a disorder, depression scores were within normal limits. For parents of children with ADHD, scores reflected mild to moderate levels of depression. Parents of children without a disorder were in the normal score range for anxiety, while parents of Down syndrome children reached mild levels of anxiety and parents of children with ADHD were in the severe anxiety range. All three parent groups were within the normal range for stress scores. For each distress factor, parents of children without a disorder scored the lowest, while parents of children with ADHD scored the highest. Descriptive statistics for each parent group can be found in Table 5.

Table 5

Comparisons of Parents of children with Down syndrome, ADHD and No Disorder on Model Indicators

<i>Variable</i>	<i>Parents of Children with Down Syndrome</i>		<i>Parents of Children with ADHD</i>		<i>Parents of Children without a Disorder</i>		<i>F</i>	η^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Depression	8.67	8.99	13.74	8.23	5.09	6.20	20.88*	.167
Anxiety	8.62	9.29	15.67	10.21	6.00	8.08	20.22*	.163
Stress	5.24	6.88	9.84	8.26	3.32	5.28	15.01*	.126
Social Support	16.60	12.40	23.34	7.62	17.55	13.24	9.91*	.087
Economic Support	4.07	3.36	5.75	3.21	3.86	3.86	7.15*	.064
Conduct Problems	5.42	5.23	11.21	5.25	3.23	3.94	50.70*	.328
Aggressive Behaviour	.80	0.87	1.55	0.96	.64	.78	21.85*	.174
Limit Setting Ability	18.02	14.65	26.71	11.83	14.05	14.33	18.30*	.150
Parental Locus of Control	35.91	33.05	52.21	25.13	28.64	31.02	13.51*	.115

*= $p < .006$

Bonferroni adjusted (.006) one-way between groups ANOVAs were conducted to compare parents of children with Down syndrome, parents of children with ADHD and parents of children without a disorder on each variable, excluding Down syndrome severity. Bonferroni corrections were used in order to control for false-positive results that can arise from conducting multiple comparisons. Significant differences were found between parent groups on all indicators. Effect sizes were between $\eta^2 = .064$ and .487, falling in the medium to high range.

In order to break down each interaction, bonferroni adjusted (.006) independent samples *t*-tests were conducted on each parental group pair. Parents of children with Down syndrome scored significantly lower than parents of children with ADHD on every indicator including socio-economic support measures. Effect sizes were moderate to high for each indicator, ranging from .50 – 1.14. A full list of effect sizes can be found in Table 6. While the lower levels of parental distress, externalising behaviours and maladaptive parental cognitions were expected considering the Down syndrome advantage, lower levels of social and economic support were not.

Table 6

Down syndrome and ADHD t-tests

<i>Variable</i>	<i>t</i>	<i>d</i>
Depression	-3.45**	.60
Anxiety	-4.05**	.71
Stress	-3.33**	.58
Social Support	-3.41**	.74
Economic Support	-2.96*	.52
Conduct Problems	-6.33**	1.10
Aggressive Behaviour	-4.58**	.80
Limit Setting Ability	-3.57**	.69
Parental Locus of Control	-3.00*	.59

$p < .006 = *$, $p < .001 = **$

No significant difference was found between parents of children with Down syndrome and parents of children without a disorder on all indicators. There were, however,

small to moderate effect sizes indicating higher levels of parental distress (depression, anxiety and stress), parental maladaptive cognitions, and conduct problems in the parents of children with Down syndrome sample, ranging from $d = .23 - .47$. The full list of effects sizes can be found in Table 7.

Table 7

Down Syndrome and No Disorder t-tests

<i>Variable</i>	<i>t</i>	<i>d</i>
Depression	2.19	.46
Anxiety	1.42	.30
Stress	1.48	.31
Social Support	-.35	.07
Economic Support	.27	.06
Conduct Problems	2.24	.47
Aggressive Behaviour	.93	.19
Limit Setting Ability	1.30	.28
Parental Locus of Control	1.07	.23

$p < .006 = *$, $p < .001 = **$

Parents of children with ADHD scored significantly higher than parents of children without a disorder on every indicator including socio-economic support measures. Effect sizes were moderate to large, ranging from $d = .53 - 1.50$. The full list of effect sizes can be found in Table 8.

Table 8

ADHD and No Disorder t-tests

<i>Variable</i>	<i>t</i>	<i>d</i>
Depression	6.25**	1.08
Anxiety	5.55**	.96
Stress	5.87**	.83
Social Support	2.43	.53
Economic Support	2.83*	.55
Conduct Problems	8.64**	1.50
Aggressive Behaviour	5.88**	.92
Limit Setting Ability	5.07**	.96
Parental Locus of Control	4.43**	.84

$p < .006 = *$, $p < .001 = **$

Correlations

Within the parents of children with Down syndrome population, correlations between each indicator and the outcome variables (depression, anxiety and stress) were found to be moderate to large and significant, excepting social and economic support. While economic support was significantly and positively correlated with depression and anxiety, correlations were small for each outcome variable. A full summary of inter-correlations can be found in Table 9.

Table 9

Summary of inter-correlations between variables in parents of children with Down syndrome

Indicator	1	2	3	4	5	6	7	8	9	10
1. Dep	-	-	-	-	-	-	-	-	-	-
2. Anx	.81**	-	-	-	-	-	-	-	-	-
3. Stress	.85**	.89**	-	-	-	-	-	-	-	-
4. SoSup	.16	.19	.21	-	-	-	-	-	-	-
5. EcSup	.35*	.36*	.20	.21	-	-	-	-	-	-
6. ConPr	.76**	.83**	.78**	.21	.34*	-	-	-	-	-
7. Agg	.66**	.64**	.64**	.13	.38*	.81**	-	-	-	-
8. LimS	.75**	.72**	.62**	.15	.60**	.87**	.76**	-	-	-
9. Ploc	.80**	.73**	.70**	.25	.52**	.82**	.62**	.86**	-	-
10. DS	.71**	.70**	.60**	.14	.57**	.83**	.71**	.95**	.81**	-

$p < .05 = *$, $p < .001 = **$

Before regression analysis was conducted, model indicators were correlated in the whole sample to determine whether any issues with collinearity were present. Correlations between depression, anxiety and stress were all above 0.8. This collinearity violation was not an issue for the current study as each factor was used in a separate regression model.

A correlation above .8 was also found between limit setting and locus of control. While this did present a collinearity issue, in order to test whether the same variables from Model A were predictive in a new sample, all variables had to be included. For this reason forced entry regressions were performed including both limit setting and locus of control. High correlations were found between most other variables within the current sample,

however all others were below .8. All VIF values were below 10, while all tolerance values were above .02, indicating there were no issues with multicollinearity. The full list of correlations can be found in Table 10 (Appendix I).

Regression Analysis

Three forced-entry regressions were used to determine whether the same factors found to predict stress, anxiety and depression in parents of children with ASD could be used to predict stress, anxiety and depression in the current sample. The Down syndrome severity measure had to be excluded from the analysis due to the mixed sample, however conduct problems and aggression scales remained as measures for child-specific factors. In the first model for depression, conduct problems and aggression were included, accounting for 63.1% of variance, $F(2, 207) = 176.62, p < .001$. Social support, economic support, parental locus of control and limit setting ability were added in the second model, accounting for an additional 2% of variance. This model was found to be significant, $R^2 = .65, F(6, 203) = 62.99, p < .001$.

Table 11

Unstandardised (B) and Standardised (B) Regression Coefficients, and beta coefficients for predictors conduct problems, aggression, social support and economic support when predicting depression

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Conduct Problems	.95	.09	.66	.85	.11	.59
Aggression	1.54	.53	.18	1.27	.54	.14
Social Support				-.01	.04	-.01
Economic Support				.13	.13	.01
Limit Setting				-.10	.07	-.16
Locus of Control				.09	.03	.30
R^2 Change		.63			.02	
<i>F</i> Change		176.62			2.91	

In the first model for anxiety, conduct problems and aggression were included, accounting for 55.3% of the variance, $F(2, 207) = 128.00, p < .001$. Social support, economic support, parental locus of control and limit setting ability were added in the second model, accounting for an additional 1.5% of variance. This model was found to be significant, $R^2 = .568, F(6, 203) = 44.53, p < .001$.

Table 12

Unstandardised (B) and Standardised (B) Regression Coefficients, and beta coefficients for predictors conduct problems, aggression, social support, economic support, limit setting and locus of control when predicting Anxiety

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Conduct Problems	.96	.11	.23	.83	.14	.48
Aggression	2.45	.70	.56	2.12	.71	.20
Social support				.03	.06	.03
Economic				-.27	.17	-.08
Limit Setting				.03	.09	.03
Locus of Control				.05	.04	.14
R^2 Change		.55			.02	
F Change		128.00			1.80	

In the first model for stress, conduct problems and aggression were included, accounting for 49.6% of the variance, $F(2, 207) = 101.70, p < .001$. Social support, economic support, parental locus of control and limit setting ability were added in the second model, explaining an additional 3.8% of variance. This model was found to be significant, $R^2 = .533, F(6, 203) = 38.67, p < .001$.

Table 13

Unstandardised (B) and Standardised (B) Regression Coefficients, and beta coefficients for predictors conduct problems, aggression, social support, economic support, limit setting and locus of control when predicting stress

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Conduct Problems	.70	.09	.54	.75	.11	.58
Aggression	1.71	.56	.21	1.67	.56	.21
Social support				.02	.04	.03
Economic support				-.35	.13	-.15
Limit Setting				-.15	.07	-.26
Locus of Control				.09	.03	.03
R^2 Change		.50			.04	
F Change		101.70			4.10	

Discussion

Due to the small sample size, we could not determine whether our results supported the first hypothesis: that the model would account for a significant proportion of the variance in predicting mental health outcomes of parents with Down syndrome children. 233 participants were needed in order to achieve enough power to find a moderate effect size if structural

equation modeling was to be performed. With a sample of only 45 parents of children with Down syndrome, this analysis was not possible and would have violated a number of statistical assumptions. Regression analysis was considered as an option to explore whether Model A predictors were predictive for parents of children with Down syndrome, however the small sample size again posed issues. It has been recommended that there should be a minimum of 10 – 15 observations per predictor when performing regression analyses (Babiyak, 2004). Considering that Model A consists of 7 predictors, a sample size of at least 70 would have been needed to ensure reasonably accurate results. Including only those predictors that highly correlated with the outcome variables was also considered, however the number of predictors remained too high, thus analysis could not be performed.

The second hypothesis, that the model would demonstrate invariance between parents of children with Down syndrome and parents of typically developing children, was again unable to be verified by our results due to sample restraints. A new set of analyses was determined in order to explore the data collected. Correlational analysis was performed on the data from parents of children with Down syndrome to determine whether relationships existed between variables. Comparisons of all three parent-groups were conducted, in order to examine differences in scores for each variable. Forced entry regressions were performed on the entire sample (parents of children with Down syndrome, ADHD and no disorder) in order to determine whether the same predictors used in Model A were predictive of distress in parents of children more generally.

Correlational analysis revealed significant correlations between predictor and outcome variables in the parents of children with Down syndrome sample. These results indicate that conduct problems, aggression, limit setting ability, parental locus of control and Down syndrome severity are likely to be predictive of distress in parents of Down syndrome children. The correlations between social support and the distress measures were non-

significant however, indicating that social support may not play a role in distress amongst parents of Down syndrome children. Correlations between economic support and distress factors were also small, with the relationship between economic support and stress being non-significant. This suggests that Model A may not be applicable to this parental group; instead a model excluding social and economic support may be a better fit for parents of children with Down syndrome.

The *t*-tests conducted between each parent sample provide some evidence of differences between these parent groups. While parents of Down syndrome children did not score significantly higher on measures of distress, conduct problems and maladaptive parental cognitions than parents of typically developing children, the effect sizes were small to moderate, ranging from .23 to .47. This suggests that there is an effect of parental group on these variables, and if the sample size were larger, it is possible that a significant result could have been found. This supports prior research findings regarding parents of Down syndrome children; while differences are small, these parents are still experiencing higher levels of distress than their counterparts with typically developing children. The fact that parents of children with Down syndrome also appear to experience higher levels of maladaptive cognitions, and their children higher levels of conduct problems, also gives some insight into why these distress levels differ. In the case of parents of children with Down syndrome, it appears likely that these factors are the ones contributing to increases in distress, with socioeconomic factors having little to no input.

The final hypothesis, that parents of children with Down syndrome would experience higher levels of social and economic support than parents of children with ADHD, was not supported by our results. Parents of children with ADHD were found to score significantly higher on all variables, including social and economic support. These findings indicate that parents of children with Down syndrome receive significantly less social and economic

support, while also experiencing significantly less distress. Differences in levels of social support may be due to the nature of both these disorders. The Down syndrome advantage has been attributed to the fact that Down syndrome children are generally easygoing and display fewer behavioural problems than children with other disorders (Mitchell, Hauser-cram and Crossman, 2015). In contrast, ADHD is characterized by behavioural problems typified by hyperactivity, inattention and impulsiveness (Podolski & Nigg, 2001). The mere fact that children with Down syndrome are easier to take care of than children with other disorders such as ADHD, may be enabling these parents to cope with less social support than parents of children with other disorders. With less of a need for social support, parents of children with Down syndrome are less likely to seek it out or rely on it, resulting in the lower levels found in this study.

Parents of Down syndrome children may also need less social support because of the social acceptance of the condition. Down syndrome is a well-known disorder that can be easily identified due to its visual characteristics, so parents of children with the disorder rarely experience disapproval from others if their child acts in atypical ways. ADHD on the other hand has no visible markers, resulting in the parents of these children being blamed for their misbehaviours. There are also many people who doubt the existence of ADHD, instead believing the parents are creating excuses for their child's disruptive behaviours (McIntyre & Hennessy, 2012). With society being less understanding of ADHD as a disorder, it appears likely that parents of children with ADHD would have a stronger motivation to seek out support than parents of children with Down syndrome.

The differences in economic support may be due to the parent sample. It is possible that the parents of children with Down syndrome who responded to this survey consisted of those with lower economic support; participants included in this study may not be representative of parents of children with Down syndrome or ADHD as a whole. Due to the

methods used to recruit participants, it is unclear whether some demographic groups may have been underrepresented. It may be that those parents of Down syndrome children with higher levels of economic support are less likely to utilise online support. There are a large number of support options for parents of children with Down syndrome, with many communities forming local support groups that are only loosely affiliated with larger, worldwide organisations (Gibson, 2014). It is feasible to believe that those parents with higher incomes live in areas where local support is more readily available, making them less likely to access the online support sites where this study was advertised.

These results do provide implications about the Down syndrome advantage. The findings regarding social and economic support suggest that the advantage does exist, and that factors previously thought to disprove the advantage may actually have very little impact on how well parents of children with Down syndrome cope with their child's disorder. In line with the Down syndrome advantage, parents of children with ADHD were found to experience significantly higher levels of distress, maladaptive cognitions and child conduct problems compared to parents of children with Down syndrome. These results appear to indicate that the dispositional and behavioural attributes of Down syndrome children make their disorder easier for parents to cope with, resulting in lower levels of distress.

It is possible within our sample that the Down syndrome children of these parents were not fully representative of the Down syndrome population. As found by Griffith, Hastings, Nash and Hill (2009), once parents were matched based on a number of variables, including the communicational capacity of their child, there were no significant differences in distress between parents of children with Down syndrome and parents of children with Autism. If the Down syndrome children of the parents recruited displayed more of the possible behavioural issues that can arise with the disorder, a different result may have been found, with these parents experiencing similar levels of distress to the parents of children

with ADHD. It appears that while there is a Down syndrome advantage, with Down syndrome children typically displaying fewer behavioural issues, there are still those children more impacted by the disorder whose parents are experiencing high levels of distress. This implies that it is not the child's disorder that causes discrepancies in parental distress, rather the behavioural problems that manifest from it.

The forced entry regression analyses conducted for depression, anxiety and stress in the whole sample provide some support for the second hypothesis, further supporting Bones' (2017) findings regarding Model A's universality. As was expected, child externalising behaviours were significant contributors to each outcome variable by themselves, and the model continued to hold once socioeconomic factors and maladaptive cognitions were included. The fact that these factors remained predictive in a sample including parents of children with two different disorders, as well as no disorder, is particularly indicative of the model's relevance to all parents. These results suggest that there are no unique factors contributing to distress levels in parents of children with particular disorders. Instead it further supports Bones' (2017) idea that the predictors are universal, with varying scores on the measures being predictive of mental health outcomes, and not particular factors being predictive for certain parent groups.

The low contributions of social and economic support in the regression models were an interesting find. Unlike Falk et al.'s (2014) findings regarding these factors for parents of children with Autism, in the current sample their contribution appears minimal. Economic support did make a reasonable contribution to parental stress, with a beta score of -.15, however for the other distress factors beta scores remained low. This finding may be due to other factors obscuring their contribution, however considering the lower correlations found between these factors and others in Model A, as well as the positive relationship between these factors and distress, their role appears questionable. It is possible that the cost of raising

a child with ASD is higher than that of raising a child with Down syndrome, ADHD or no disorder, thus economic support has a bigger impact on anxiety and depression in parents of these children. In comparison to parents of children with Down syndrome, parents of children with ASD have been found to report a higher need for child-centred therapies (Siklos & Kerns, 2006). This suggests that, at least compared with parents of Down syndrome children, parents of children with ASD are unsatisfied with the child interventions readily available, leading to financial issues when seeking better treatment.

Implications for parental interventions

These results imply that although parents of children with Down syndrome appear to experience lower levels of distress than parents of children with other disorders, such as ADHD, their distress levels are still elevated compared with parents of typically developing children. As Griffith, Hastings, Nash and Hill's (2009) study suggests, for parents of Down syndrome children more impacted by their disorder, distress levels are higher, indicating a need for interventions tailored specifically for this parent group. Unlike parents of children with ASD however, it appears that interventions for parents of children with Down syndrome should place less emphasis on socioeconomic factors, instead focusing on altering maladaptive parental cognitions.

Cognitive Behavioural Therapy (CBT) is commonly used to treat a wide range of psychological disorders. It has been found to be an effective form of treatment for the distress factors included in this study with intervention effects persisting long after treatment has ended (Butler, Chapman, Forman & Beck, 2006). The cognitive behavioural approach suggests that it is cognitions that lead to the development and maintenance of maladaptive behaviours and emotions, resulting in mental disorders (Hofmann, Asnaani, Vonk, Sawyer & Fang, 2012). With maladaptive cognitions being the main factors, other than child specific ones, found to be elevated in parents of children with Down syndrome, this form of therapy

has the potential to be particularly beneficial. CBT works by altering the cognitions that are leading to feelings of depression, anxiety and other negative mood states (Hofmann et al., 2012). Targeting cognitions like parental locus of control and perceived limit setting ability should increase feelings of control and competency in parents of children with Down syndrome, ultimately reducing distress.

While little research has been conducted into the effectiveness of CBT for parents of children with Down syndrome, research into parents of children with a broad range of developmental disabilities has found it to be beneficial (Singer, Ethridge & Aldana, 2007). Through conducting a meta-analysis of 17 studies, Singer, Ethridge and Aldana (2007) found CBT-based interventions to be effective in reducing psychological distress in parents of children with developmental disorders. The study also found evidence to support CBT's positive impact in the long term. An additional finding of the study was that interventions with multiple components were more effective than CBT alone. Behavioural parent training and family-focused interventions were outlined as targeting different components of distress, adding to the effectiveness of CBT.

The effect of parent-focused CBT on child outcomes remains unknown at the present. It is, however, evident through a number of studies that parental mental health can impact a parent's ability to effectively control their child's behaviour, their appraisals of their child, and how they interact with them (Burke, 2003; Hastings, 2009; Ramchandani et al., 2011; Moore, Whaley & Sigman, 2004). Considering the crucial role that parent-child interactions have been found to play in the development of Down syndrome children (Mahoney, Perales, Wiggers & Herman, 2006), it makes intuitive sense for improvements in parental psychological functioning to improve a parent's capacity to support and implement intervention techniques for their child.

Limitations

The study used a correlational design, thus could not fully confirm the relationships between predictors and outcome variables. To provide further support for factor relationships, future research could involve a longitudinal study, investigating whether changes in predictor variables over time resulted in changes in outcome variables.

Secondly, participant numbers were too low to properly test Model A. As a result, it is unclear whether Model A could be predictive of distress in parents of children with Down syndrome. In order to properly test the model a larger sample size would be needed, with at least 230 parents of children with Down syndrome and 230 parents of typically developing children to address the first two hypotheses.

Thirdly, the nature of participant recruitment meant that we were unable to confirm whether our sample was representative of the general public. Recruitment occurred through a variety of outlets, the majority being through online support groups and organisations. Those who use these groups may only represent a specific portion of the parental population for Down syndrome and ADHD children. As previously addressed, parents with community resources outside of internet-based support may not be utilising the sites through which the study was advertised. Additionally those parents with children who are more impacted by their disorder may not have time to access such sites or to complete the questionnaire.

Fourthly, the length of the questionnaire may have discouraged some people from responding to the survey. In order to test Model A in a new sample, it was important to use all the same measures, resulting in participants needing to answer a large number of questions. This may have contributed to the small number of respondents with Down syndrome children; these parents may have felt that the time required to complete the questionnaire was unwarranted considering the fact that their children are easier to manage than others with developmental disorders.

An additional limitation for this study is that it did not include all factors found to contribute to distress in parents of children with Down syndrome. Model A was created based on factors that have been found to be predictive of distress in parents of children with Autism. While a number of studies have found these same factors to be predictive for parents of Down syndrome children, this does not rule out the possibility that alternative factors may better explain distress differences in this parent group. Previous studies involving parents of children with Down syndrome have also found self-efficacy, spousal support and coping styles to be predictive of parental distress (Dabrowska & Pisula, 2010; van der Veek, Kraaij & Garnefski, 2009).). It is possible that a model including these factors instead of socioeconomic support would provide a better fit.

Another issue with the current study was that fathers comprised only 6.6% of those who answered the survey. It is possible that fathers experience distress for different reasons than mothers, whether the child has Down syndrome, ADHD or no disorder. While Model A has been found to be predictive of distress in fathers of children with Autism (Falk, Norris & Quinn, 2014) this may not be the case for all fathers. In order to conduct invariance testing, future research should aim to recruit high numbers of both mothers and fathers of children with Down syndrome.

Future research

As previously discussed, future research should involve testing Model A in parents of children with Down syndrome. Invariance testing between parents of children with and without Down syndrome would also assist in determining Model A's universality. Recruiting a larger number of fathers for future research into Model A's applicability would also be beneficial. Additionally, parental dyads could be recruited to examine whether Model A is predictive of distress for parents of the same child.

Future research could also investigate whether an alternative model, not including socioeconomic factors, would be a better fit for parents of children with Down syndrome. As previously mentioned, factors including self-efficacy, spousal support and coping style have been found to be predictive of mental health outcomes in parents of children with Down syndrome (Dabrowska & Pisula, 2010; van der Veek, Kraaij & Garnefski, 2009). Whether these factors could prove to be better mediators between child externalising behaviours and distress outcomes for this parent group would be worth exploring.

The impact of parent CBT on child outcomes has received little attention. Research into whether such parent interventions can lead to functional and cognitive improvements in children with developmental disorders such as Down syndrome would provide support for the utilisation of distress models such as Model A. It would support the idea that child interventions should use a holistic approach; addressing not just the child's needs, but also those of their family. Currently, interventions for children with Down syndrome mainly target child specific factors, with parents being educated about intervention implementation and how to improve interactions with their child (Patton & Hutton, 2016; Mahoney, Perales, Wiggers & Herman, 2006). Being able to promote the benefits that addressing parental mental health has on their children's wellbeing could be crucial in bringing about lasting changes in intervention approaches.

Conclusion

This study's findings indicate that while the Down syndrome advantage does exist, parents of children with the disorder still experience elevated levels of distress compared with parents of typically developing children. Children with Down syndrome do appear less likely to display behavioural problems than children with other disorders such as ADHD, yet this does not eliminate the need for parent-centred interventions.

While the results of this study did provide further support for Model A's universality, the findings regarding social and economic support indicate that an alternative model could provide a better fit. Until Model A can be properly tested in a larger sample, its predictive value for parents of children with Down syndrome cannot be fully determined, however the current findings do suggest that additional factors should be explored. The fact that Model A predictors were found to hold for the whole sample supports previous findings indicating that it is not just child behaviours that contribute to parental distress; additional factors such as maladaptive cognitions can also play a significant role (Falk, Norris & Quinn, 2014; Bones, 2017). These findings support the need for a more holistic approach where children with disabilities are concerned, with parental distress factors being addressed alongside child-focused therapies. CBT aimed at reducing maladaptive parental cognitions may be of particular benefit for parents of children with Down syndrome, with further research being needed to determine whether additional parent factors are worth targeting.

These findings have important implications regarding current interventions for children with Down syndrome and their families. Educating parents about how to implement child therapy techniques and manage child behaviour problems may not be enough to eliminate parental distress. In ignoring additional factors impacting parents of children with Down syndrome, current interventions are leaving parents at risk of being unable to properly administer taught therapy techniques or provide the high level of support their child requires. The development of interventions aimed at addressing the needs of both the child and their parents should not only help reduce parental distress, but also optimise child outcomes.

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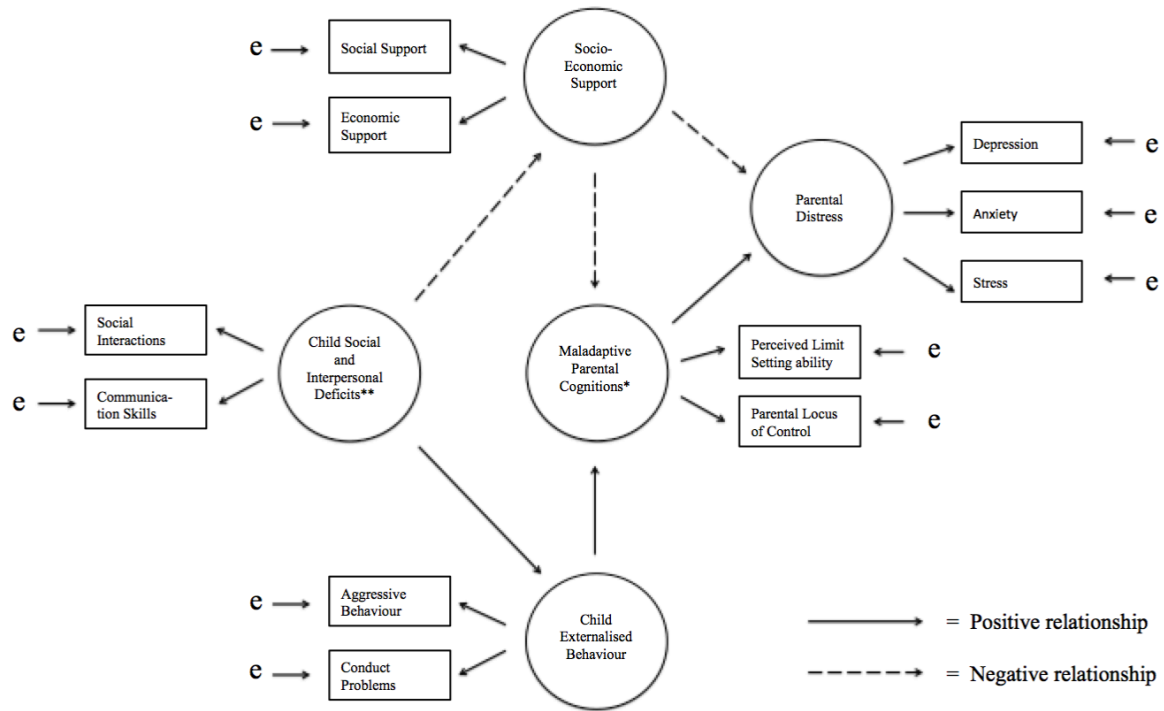
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Appendix A

Model A



*Figure 1. Model A. e = error variance. Circles represent latent variables (factors); rectangles represent observed variables (indicators). Solid lines represent positive relationships; broken lines represent negative relationships. * Parental Cognitions was altered to Maladaptive Parental Cognitions for ease of interpretation ** ASD Severity was altered to Child Social and Interpersonal Deficits to facilitate use in non-ASD samples. Adapted from “The Factors Predicting Stress, Anxiety, and Depression in the Parents of Children with Autism” by N. H. Falk, K. Norris, and M. G. Quinn, 2014, *Journal of Autism and Developmental Disorders*, 44, p. 3196. Copyright 2014 by N. Falk.*

Appendix B

Ethics Approval Letter

Social Science Ethics Officer
Private Bag 01 Hobart
Tasmania 7001 Australia
Tel: (03) 6226 2763
Fax: (03) 6226 7148
Katherine.Shaw@utas.edu.au



HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

09 May 2018

Dr Kimberley Norris
Psychology
Private Bag 30

Dear Dr Norris

Re: FULL ETHICS APPLICATION APPROVAL
Ethics Ref: H0017272 - Testing a Model Predicting Depression, Anxiety and Stress in
Parents of Children with Down's Syndrome and Attention-Deficit/Hyperactivity Disorder

We are pleased to advise that the Tasmania Social Sciences Human Research Ethics Committee approved the above project on 09 May 2018.

This approval constitutes ethical clearance by the Tasmania Social Sciences Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approval of other bodies or authorities is required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.
2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or human.ethics@utas.edu.au.

A PARTNERSHIP PROGRAM IN CONJUNCTION WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

3. Incidents or adverse effects: Investigators should notify the Ethics Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
4. Amendments to Project: Modifications to the project must not proceed until approval is obtained from the Ethics Committee. Please submit an Amendment Form (available on our website) to notify the Ethics Committee of the proposed modifications.
5. Annual Report: Continued approval for this project is dependent on the submission of a Progress Report by the anniversary date of your approval. You will be sent a courtesy reminder closer to this date. **Failure to submit a Progress Report will mean that ethics approval for this project will lapse.**
6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely

Jude Vienna-Hallam
Acting Executive Officer
Tasmania Social Sciences HREC

Appendix C

Participant Information Sheet



Participant Information Sheet V.01, / /17

TESTING A MODEL PREDICTING DEPRESSION, ANXIETY AND STRESS IN PARENTS OF CHILDREN WITH ATTENTION-DEFICIT/HYPERACTIVITY DISORDER AND DOWNS SYNDROME

Invitation:

You are invited to participate in a research study examining the factors predicting depression, anxiety and stress in parents of children with Attention-Deficit/Hyperactivity Disorder (ADHD) and Down syndrome. We are also interested in validating a model predicting parental distress for all parents, not just those who have children with physical or psychological conditions. This study is being conducted by student researchers Sarah Scott and Johanna Van Der Hek as part of the requirements for the Honours Psychology Program at the University of Tasmania, under the supervision of Dr Kimberley Norris.

Before deciding whether or not you would like to participate, please read through the following information so that you have an understanding of the purpose of the study, what it will involve, and any risks and benefits of participating.

1. What is the purpose of the study?

The purpose of this study is to examine the factors that predict depression, anxiety and stress in the parents of children with ADHD and Down syndrome. Furthermore, we aim to provide validation for a model of general parental distress.

2. Why have I been invited to participate?

You have been asked to participate because you have a child aged between 4 years 0 months and 17 years 11 months. Your child may have ADHD, Down syndrome, or no diagnosed condition.

3. What will I be asked to do?

Should you choose to participate in this study, you will be asked to complete a once-off online survey. This survey will contain questions asking about your mental health, your child's symptoms and behaviour, and your social and economic support, as well as some demographic information. Responses will be multiple-choice style.

Your participation is entirely voluntary, and you may discontinue your participation at any time prior to the submission of the questionnaire. As your data is non-identifiable, in that we don't ask for your name or other identifying information, once you have submitted your responses we cannot remove them as there is no way of identifying which data belong to you.

4. Are there any possible benefits from participation in this study?

This study gives parents the opportunity to discuss their mental health and the impact that their child's behaviour or disorder has on them. This study may therefore provide an opportunity for parents to have their voices heard and discuss issues in a confidential and anonymous way.



Participant Information Sheet V.01, / /17

This study may also give parents the opportunity to contribute to the scientific understanding of ADHD and Down syndrome beyond the affected child's experience. This study may help explain parental distress, provide evidence for a model of parental distress, and may inform interventions to help prevent/treat parental distress in parents of children with ADHD, Down syndrome, as well as children not affected by any physical or psychological condition.

It is also possible that you may gain feelings of satisfaction from being able to contribute to a study that could have impacts on many families with a child with ADHD or Down syndrome.

Additionally, participants in this study may choose to go into the draw to win one of eight \$50 Coles-Myer vouchers as thanks for their participation.

5. Are there any possible risks from participation in this study?

This study involves answering questions about your mental health, and your child's disorder and behaviour, which could evoke some anxiety. If you feel any distress during the questionnaire we encourage you to immediately discontinue the study. If you wish to discuss these feelings with someone, you are welcome to contact Dr Kimberley Norris on the phone number or email address at the bottom of this document, or engage with other support services such as Lifeline (13 11 14) or Beyond Blue (1300 22 4636).

If you have any concerns or questions about the study, please feel free to contact Dr Kimberley Norris.

6. How will my confidentiality be protected?

As previously mentioned, data will be entirely non-identifiable and will only be accessible to the researchers. Raw data will be destroyed after five years.

7. What if I change my mind during or after the study?

Participation in this study is entirely voluntary and you may withdraw at any point prior to the submission of the questionnaire. As your data is non-identifiable, once you have submitted your responses we cannot remove them as there is no way of identifying which information belongs to you.

8. What will happen to the information when this study is over?

The data from this study will be stored for five years on a secure computer. Data will be destroyed after five years.

9. How will the results of the study be published?

Preliminary results will be available in December 2018. If you would like a copy of these results you can access these on the University of Tasmania Psychology website located at: <http://www.utas.edu.au/health/study/psychology>. Results of the study will also be published on facebook sites on which the study was advertised. It is also anticipated that the researchers will publish this study in an academic journal.

If you would like to personally receive a summary of the results, please contact the researchers via the email address provided below.



Participant Information Sheet V.01, / /17

10. What if I have questions about this study?

If you have questions about the study, feel free to contact student researchers Sarah Scott or Johanna Van Der Hek, or Chief investigator Dr Kimberley Norris.

Contact details:

- Student Researchers: Sarah Scott (slscott0@utas.edu.au)
Johanna Van Der Hek (jvander@utas.edu.au)
- Chief Investigator: Kimberley Norris (Kimbeley.norris@utas.edu.au) or 6226 7199).

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have any concerns or complaints regarding the conduct of this study, please contact the executive officer of the HREC (Tasmania) Network on +61 3 6266 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number: [H0017272](#).

Thank you for taking the time to consider participation in this study. Completing and submitting the questionnaire on the online survey will be taken as explicit consent to participate in this study.

Appendix D

Demographic Variables

Table D1
Summary of Parent Categorical Demographic Variables

<i>Variable</i>	<i>Category</i>	<i>N</i>	<i>%</i>
Primary care giver	Yes	180	85.3
	No	6	2.8
	Not reported	25	11.8
Parent sex	Female	173	82
	Male	14	6.6
	Not reported	24	11.4
Education level	Below year 12	6	2.8
	Year 12	32	15.2
	Vocational	29	13.7
	Diploma	16	7.6
	Bachelor	54	25.6
	Post grad	46	21.8
	Other	11	5.2
Marital status	Not reported	17	8.1
	Married	135	64
	Defacto	27	12.8
	Divorced	17	8.1
	Widowed	2	.9
	Single	9	4.3
	Not reported	21	10
Employment status	Fulltime	66	31.3
	Part time	62	29.4
	Unemployed	60	28.4
	Not reported	23	10.9
Total annual income	\$0-19,999	43	20.4
	\$20-49,999	69	32.7
	\$50-79,999	30	14.2
	\$80,000+	39	18.5
	N/A	10	4.7
	Not reported	20	9.5
Total Annual income household	\$0-19,999	7	3.3
	\$20-49,999	33	15.6
	\$50-79,999	43	20.4
	\$80-120,000	53	25.1
	\$120,000+	49	23.1
	Not reported	26	12.3

Table D2

Summary of Child Categorical Demographic Variables

<i>Variable</i>	<i>Category</i>	<i>N</i>	<i>%</i>
Child Sex	Female	65	30.8
	Male	123	58.3
	Not reported	23	10.9
Birth order	Youngest	61	28.9
	Middle	31	14.7
	Eldest	64	30.3
	Only	34	16.1
	Not reported	21	10

Table D3

Summary of Continuous Demographic Variables

<i>Variable</i>	<i>M</i>	<i>SD</i>
Child age (years)	9.10	3.00
Parent age	41.86	8.08
Number of people living in household	4.30	1.20
Number of children living in household	2.20	1.10

Appendix E

Advertisement flyer

Are you a parent? Do you have a child aged between 4 and 17?

How can you help?

We want to examine the factors associated with parental distress in parents of children with ADHD and Down syndrome. Your participation could help us predict parental distress in parents of children with ADHD and Down syndrome, which could inform treatment interventions.

We are looking for parents of children with ADHD, Down syndrome AND parents of children with no disability.



Interested?

Scan the QR code on your phone or follow the link to complete our online survey: <https://tinyurl.com/y8dkx9a7>.

The survey should take around 45-60 minutes.

Participants can also go in the draw to win one of eight \$50 Coles-Myer vouchers.

Scan the QR code by opening your smartphone's camera app and holding the camera over the QR code.

No need to hit the shutter button – your device will automatically recognize the code and take you to our survey.

Student researchers: Johanna Van Der Hek (jvander@utas.edu.au) and Sarah Scott (slscott0@utas.edu.au). Ethics Approval number: H0017272

Appendix F

Economic support questions

You have a special person who is willing and able to help you financially: Strongly Disagree; Disagree; Neither Agree Nor Disagree; Agree; Strongly Agree.

You have some family or friends who are willing and able to help you financially: Strongly Disagree; Disagree; Neither Agree Nor Disagree; Agree; Strongly Agree.

Appendix G

Demographic questions

About the parent:

1. Has your child ever been diagnosed with a mental or physical health condition? Yes/no
[if no, skip items 2 and 3 and only see questionnaires labeled ‘all participants’]
2. Do you have a child with a diagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD)? [if yes, only see items relevant to ADHD parental experience]
3. Do you have a child with a diagnosis of Downs syndrome? [if yes, only see items relevant to Downs syndrome parental experience]
4. What is your year of birth:
5. What is the highest level of education you have completed: Some High School (years 7-10) ☐ High School (years 7-10) ☐ Some College (Years 11 and 12) ☐ College (years 11 and 12) ☐ Some University ☐ University Degree ☐ Post Graduate ☐
6. Including yourself, how many people live in your household?
7. How many children, under the age of 18, currently live in your household?
8. How many of your children have received a diagnosis of ADHD/Downs syndrome (*participants will only see the information relevant to their earlier responses, e.g. if they indicated they had a child with ADHD it would read “...have received a diagnosis of ADHD; if Downs syndrome, “....have received a diagnosis of Downs syndrome)”*)?
9. What is your relationship status? Married ☐ De Facto relationship ☐ Separated/Divorced ☐ Widowed ☐ Single ☐ Other ☐ Please specify
10. What are your living arrangements? Married couple living together ☐ Married couple living apart ☐ Defacto couple living together ☐ Defacto couple living apart ☐ Single ☐ Other ☐ Please specify
11. Are you currently employed? Full time ☐ Part time ☐ Not employed ☐

12. What is your total annual income, before taxes: \$0-19,999 ☐ \$20-49,999 ☐ \$50-79,999 ☐ Over \$ 80,000 ☐ Not applicable ☐
13. What is your total household income, before taxes: \$0-19,999 ☐ \$20-49,999 ☐ \$50-79,999 ☐ \$80-120,000 ☐ Over \$120,000 ☐
14. Do you have any current diagnosed medical conditions for which you are receiving treatment? Yes ☐ No ☐

If 'yes', what medical conditions are you currently receiving treatment for?

About the child:

1. How old is your child? Years and Months.
2. What sex is your child? Male ☐ Female ☐
3. Is your child an eldest, middle, youngest or only child? Eldest ☐ Middle ☐ Youngest ☐ Only Child ☐
4. What kind of school does your child attend? Mainstream School ☐
Special Needs Day School ☐ Special Needs Boarding School ☐
Full-Time Home Care ☐ Institutional/Hospital Care ☐ Other (Please State)
5. When at home, are you the primary carer for your child? Yes ☐ No ☐
6. What is your relationship with your child? Biological Mother ☐ Biological Father ☐
Step Mother ☐ Step Father ☐ Foster Mother ☐ Foster Father ☐ Other ☐ (Please State)

Appendix H

Down Syndrome Severity Scale Questionnaire

Instructions: The following items focus on the capabilities of your Down syndrome child.

For each question, please answer by choosing yes or no.

Self-care

- | | | |
|--|-----|----|
| 1. Eats all food textures (e.g soft/hard, crunchy/mushy) | Yes | No |
| 2. Can use utensils (knife/fork/spoon) independently | Yes | No |
| 3. Can pour liquids from a carton/jug independently | Yes | No |
| 4. Can zip and unzip items independently | Yes | No |
| 5. Can dress themselves including buttons independently | Yes | No |
| 6. Can tie their shoe laces independently | Yes | No |
| 7. Can go to the bathroom by themselves, with no accidents | Yes | No |
| 8. Can control their bladder, remains dry day and night | Yes | No |

Mobility

- | | | |
|--|-----|----|
| 9. Walks without support | Yes | No |
| 10. Opens and closes doors independently | Yes | No |
| 11. Can walk up full flight of stairs with no difficulty | Yes | No |
| 12. Can walk down full flight of stairs with no difficulty | Yes | No |
| 13. Can walk long distances with no difficulty | Yes | No |
| 14. Can carry fragile objects | Yes | No |

Social Function

- | | | |
|--|-----|----|
| 15. Can talk about own feelings or thoughts | Yes | No |
| 16. Understands talk about time and sequence | Yes | No |

17. Can tell a story connecting two or more thoughts	Yes	No
18. Can carry out household tasks with a number of steps	Yes	No
19. Can solve ordinary problems with the help of an adult	Yes	No
20. Can play games or activities with rules	Yes	No
21. Uses imagination in play	Yes	No
22. Can keep track of time using a clock or asking others	Yes	No

Appendix I

Summary of inter-correlations between model indicators in whole sample

Indicator	1	2	3	4	5	6	7	8	9
1. Dep	-	-	-	-	-	-	-	-	-
2. Anx	.82**	-	-	-	-	-	-	-	-
3. Stress	.81**	.81**	-	-	-	-	-	-	-
4. SoSup	.35**	.32**	.26**	-	-	-	-	-	-
5. EcSup	.34**	.26**	.15*	.50**	-	-	-	-	-
6. ConPr	.78**	.73**	.68**	.41**	.41**	-	-	-	-
7. Agg	.64**	.63**	.60**	.29**	.31**	.71**	-	-	-
8. LimS	.67**	.64**	.54**	.46**	.47**	.79**	.66**	-	-
9. Ploc	.71**	.69**	.58**	.45**	.39**	.75**	.62**	.90**	-

$p < .05 = *$, $p < .001 = **$